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ABSTRACT

This paper describes the results of an evaluation of the Palliative Care Service, one of the first hospices in North America (Montreal), and the implications of that research for social policy development. The objectives of the research were to evaluate the reliability of predictive assessments of bereavement risk and the effectiveness of bereavement follow-up using trained and lay volunteers, to compare palliative care and general hospital wards, to ascertain if there are cultural differences in bereavement for English and French speaking groups, and to study bereavement over time. Four major results indicated that bereavement risk can be predicted in a normal population, intervention is helpful for some high risk people but not for others, the grieving process may be very different for men and women, and there are cultural differences in the bereavement process. The discussion of the implications of the research findings for policy formation focuses on evaluating the need for prevention programs, the use of professional personnel, health care costs, and the role of community psychologists in alleviating bereavement. (MCF)

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INVITED ADDRESS

Research on Bereavement: Implications for social policy development

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It is indeed a privilege to address the members of Division 27 and to welcome you to Toronto. Most of us north of the border, because of vast geographical distances, cultural diversity, and a population approximately 1/10 that of the United States, are indeed grateful that Toronto was chosen because it made it possible for more of us to attend, and, in turn, I am certain that you are delighted with the exchange rate on the U.S. dollar.

The context of this research is Canadian, but I believe there are implications for you in the United States as well. After a brief description of the study, some of the significant results will serve as the basis for the implications, I believe to be pertinent to social policy development.

The Palliative Care Service, known as the PCS, of the Royal Victoria Hospital, in Montreal, was established in 1975, by Dr. Balfour Mount, in response to the need for such care among the terminally ill. It was one of the first hospices established in North America. The service, staffed by a multidisciplinary team consists of four interrelated areas of care: 1) The Palliative Care Unit (PCU), which is the inpatient ward; 2) the consultation service which is care offered to other RVH wards; 3) the home care service, whereby staff enable patients to remain at home; and 4) the bereavement follow-up program, a preventive intervention service for key persons affected by the terminal illness and death of PCS patients.

Dr. Mount had been aware from the beginning that bereavement follow-up should be an integral part of the overall service. Studies of the last three decades, in spite of methodological difficulties, suggested that bereavement is a period of increased somatic, psychological, and social vulnerability.

Bereavement is defined as the reaction to the loss of a close relationship. It is the psychological mourning process which may be seen as a reversing or undoing of the various processes that have gone into building the relationship, or as Bak (1973) phrased it: «It is, perhaps, the reverse of love.»

Many intervention models had been developed. one of the best-known, and the model for the RVH research was that of St. Christopher's Hospice, in England, where the bereaved have been followed by home care nurses and other staff. Dr. Colin Murray Parkes (1972), found that support during the early weeks of bereavement, by such a team, can effectively reduce the incidence of depression, autonomic symptoms, externally-directed anxiety, and the consumption of tranquilizers, alcohol, and tobacco. The question arose, however, as to the degree which the holistic care offered by St. Christopher's, a financially independent institution, influences the bereavement process itself. The Palliative Care Service at the Royal Victoria is a very small unit in a large general hospital and thus desperately competing with other services for funds.

Realizing the spiraling costs of medical care, as well as the threat to health posed by intensive grief reactions, Dr. Mount saw the need

for a more structured service but was confronted with the issues of who should do bereavement follow-up and how this could be assessed. Other questions demanded clarification: Could bereavement risk be predicted? Who should be followed? What personnel are required? Is intervention different for the PCS and the general hospital? Are there cultural differences between French and English, in the unique bicultural Province of Quebec?

Dr. Mount applied for, and in July, 1978, received a grant from Health and Welfare Canada, to set up a structured, bilingual bereavement program. Separate funding from Health and Welfare Canada, in May, 1979, administered by the University of Montreal, provided for its evaluation.*

The objectives of the research were: 1) to evaluate the reliability of predictive assessments of bereavement risk; 2) to evaluate the comparative effectiveness of bereavement follow-up using trained lay volunteers and nurses; 3) to compare results for subjects from palliative care and the general hospital wards; 4) to ascertain whether cultural differences exist between French and English language groups; and 5) to assess periodically the bereavement process and outcomes over a period of 25 months. Underlying these objectives were a number of important questions, the most important of all being: Should bereavement intervention be done at all?

To achieve these objectives, the period between grant acceptance and the initiation of the program, one year later, involved the following: 1) the operational definition of bereavement intervention which meant the

*Health and Welfare Canada, 6605-1582-42B

standardization of the existing service by clarifying the goals, limits, and roles of personnel; the establishment of criteria for the selection and training of intervenors who were specially chosen for the study; initiating the necessary contacts with personnel throughout the general hospital wards; establishing the data collection system for both the program and the evaluation; and, finally, the difficult, time-consuming job of translating all materials into French and studying the validity of the translation.

The research questionnaire consisted of the following: The Goldberg General Health Questionnaire, the Parkes Symptom Check List for Depression and Autonomic Reactivity, Life Perception and Habits, Physical Conditions, Emotional State and Depression Scale, Worries Check List, Social Life, Loss and Change, Support Systems, Outcome and Adjustment, other experiences, and demographic data. The evaluators were also requested to provide a detailed commentary of their observations and impressions of the interview.

In addition to the questionnaire items, a Bereavement Coping Assessment, known as the BCA, was developed, based on the Parkes' model, and for use by the care givers. The assessment was completed as soon after the patient's death as possible. The purpose of the BCA was to determine whether staff members could predict beforehand how people would cope later with the loss.

The research began in June, 1979, when the first bereavement coping assessments were made. The procedure was as follows: one key person was identified per family of patients who had died of cancer within the PCU,

referred to as a PCU subject; and one key person, per family, of patients who died in the general wards of the Royal Victoria and the Montreal Convalescent Hospital referred to as a non-PCU subject. The key person was arbitrarily selected from those at risk, based on knowledge concerning the patient's constellation of family and friends. It is important to note that the risk assessment was not used for group allocation.

Although adhering to strict ethical procedures it was possible with few exceptions that subjects from all three sites and both language groups could be assigned randomly to either the experimental group, that is, intervention by nurse or volunteer; or the control group, non-intervention. Follow-up was begun as soon as possible after the death, which according to the literature, was the best point of entry into the process.

Evaluation interviews were scheduled for 6, 13, and 25 months after the death of the patient. At six months, when the first evaluations were due, the 11 English and 9 French evaluators set up appointments after an initial contact by telephone of a French-or English-speaking assistant. Telephone lists were kept for the 29 month evaluation period, and they contain information such as comments made by the key persons, reasons for refusal, information on those unavailable for the research, the number of calls required to reach a subject, the length of extended calls, etc. This is an exceedingly rich data bese, providing as at does, information on research participation, but on non-participation as well.

Out of a sample pool of 992, 312 subjects remain. They are divided by institution, intervention, language, sex, intervenor, and key

person relationship to patient. There are 241 evaluations at 6 months; 221 at 13 months; and 109 at 25 months, for a total of 571 evaluations. Out of the 312 subjects, 60 completed all three interview.

I have chosen four of the findings to present here. These are the statistical results of seven major segments of the questionnaire analyzed for the 60 subjects with three evaluations. Each segment consists of a series of items aimed at obtaining informaiton about a particular aspect of the bereavement process over time. It is important to note that statistical treatment revealed nothing anomalous about the 60 subjects. They are representative of our total sample of 312 subjects.

1. The first finding concerns the ability to predict bereavement risk in a normal population. Our results suggest that this can be done. We found seven items of the Bereavement Coping Assessment which were consistently accurate in predicting high and low risk. In other words, hospital personnel were quite capable of predicting outcome. The item «Coping Ability Predicted by Care Givers» is based on the compound perception of the staff caring for the patient. When the predictions were clasified into high, medium, and low risk, the means of the subjects thus clasified were found to be in proper order, on all variables, measured over three interviews without exception.

I believe this is an important finding. Up to the present time all risk profiles have been developed within a framework of therapeutic assessment, and have dealt with those considered to be at risk of malresolution of the grieving process. These subjects represent a normal, not

pathologically-at-risk population. The latter had been eliminated either before or during the study.

2. The second result was the interaction found between the intervention and time. On the Life Perception segment, which deals with one's views of life, wishes to change it, happiness, etc., the control and experimental groups interacted inversely over time. Good life perception is found in the control subjects, who score high at 6 months, dip at 13 months and come back up by 25 months, in a V shape. On the contrary, both experimental groups, that is, subjects followed by a nurse or a volunteer, have a poor life perception score at 6 months, substantially better at 13 months, but a very low score again at 25 months. Subjects from the PCS appeared to do worse than people from the general hospital milieux, where less attention is paid to what has come to be called, anticipatory grieving.

What is interesting about this finding is that if one were to look only at the results at one-year post-bereavement, intervention would appear to be helpful, but the data at two years post-bereavement indicate that the PCU subjects in this research appeared to be significantly worse off.

Similar results were found in an examination of the Physical Symptom Checklist for both groups. A symptom-by-symptom study reveals that overall, the experimental subjects have twice as many symptoms as controls. Furthermore, for the experimental the number of reported symptoms is almost twice as high post-death as pre-death, whereas, the controls reported that

symptoms changed relatively little over time.

One must be cautious in interpreting these data, a caveat which also applies to the others presented here. However, a few comments are indeed justified.

In discussing this finding with the staff, it was felt that the hospice's willingness and encouragement to talk about feelings had led those subjects to be more open and honest about their emotional states, with the results that hospice families look much worse than subjects from the general wards.

One the other hand, there are a few suggestions in the literature, combined with our content analysis of questions pertaining to anger and regret, that lead me to believe that intervention is efficacious for certain high risk people, but not for others. Nothing more definitive can be said at this time, but I feel that further analyses will confirm this finding.

These results on the interaction of intervention and time have also forced us to question whether anticipatory grieving is possible. The theory behind it is, that if part of the separation and loss are dealt with before the death, the mourning process will be less intense. After studying our material, I doubt the validity of this concept. Our data indicate that subjects in both the experimental and control groups felt guilty because they said they knew that death was inevitable; therefore, they should already have with dealt much of the pain de sadness and loss. They were disturbed about the intensity of their emotional reactions at the time of the evaluation. The attitude of society about death is eminently reflected in their fear of not coping well or quickly enough.

If anticipatory grieving does occur, it must be very difficult if not impossible to achieve. To have been in close contact day after day with a loved one, only intensified the relationship of those key persons involved in this study. They felt that they had grown very close to the individual who was dying in spite of any psychological withdrawal on the part of the patient. In essence, these subjects felt that the tie had become stronger--not weaker. Knowledge and preparedness do indeed influence the ability to cope afterwards. There is a great deal of evidence to support this, and our data strongly confirm it. However, this has little or nothing to do with that period before death, as a grieving process. Much remains before we can clarify what is meant by anticipatory grieving. I believe the process that occurs before death should be redefined with its own terminology, without the concept of anticipatory being part of that definition. With some of the subjects, having found it impossible to achieve, they then felt guilty about the very strong emotional reactions which continued to occur. We may thus be adding an unnecessary burden on the shoulders of already heavily burdened individuals.

3. The third result concerns the difference that was found between men and women on the Depression Scale. The process is an inverse one. Women were more depressed at 6 months, less at 13, and somewhat more at 25 months. The male subjects, though less depressed than women at 6 months, were more so at 13, and at 25 months, even though less depressed than women, they were more depressed that they had been at 6 months.

This finding, along with others not mentioned here, suggest that the bereavement process may be very different for men and women. The vast majority of the literature on bereavement deals with women; very few studies have dealt directly with men. The reasons for this are obvious, but that does not justify the continued neglect of studying possible differences between men and women during the fer process.

4. One of the most important objectives of this research was to determine if there were cultural differences between the French-and English-speaking subjects. One of the most clearcut and convincing results, and a main effect, was that French subjects showed better adjustment than English ones. The 15-item Adjustment Scale dealt with missing the person, memories, regrets, anger and guilt about what might have been done or said, as well as fears about death. Looking at the Adjustment Scale for all three interviews combined, the French did significantly better than the English ones. This same pattern was also found on the Life Perception Scale, where the process is significantly different. The English subjects have a high score at 6 months, but get steadily worse, whereas the French start low and become significantly better at 13 months. At 25 months, they have about the same intermediate perception of life. But the process leading up to that time is very different indeed. There were also similar differences on physical symptoms and worries.

These findings are of special significance for us in the Province of Quebec. Culture implies an underlying value system and much work remains to be done in order that clarification of those values which have contributed to these differences can be made explicit. A search of the

literature did not reveal any work done on cultural differences over time during the bereavement period. This, this future study should be an interesting--if difficult--challenge.

By way of concluding this section, I would suggest that our data do not agree with the commonly held view that the bereavement process can be represented by a gradually decreasing line towards resolution. The eventual lessening of pain does happen but this does not obviate those peaks of emotional intensity which are more disturbing to the individual the longer they persist-and that may be for a long time, indeed (Rosenblatt, 1983). As Goin et al., (1979) point out, a person can appear to have completed the work of separation required by a loss at one point, only to hit a period of intense grief when confronted with reminders of that relationship. Bowlby (1980) has written that people do not struggle constantly with their griefs; there is discontinuity (p. 231). The subjects in this study spoke of controlling their emotions some if not most of the time--but not all of the time. Parkes & Weiss (1982) noted the same pattern in their recent publication. Dr. Parkes coined the word "pangs" to describe these intense emotional moments. It is an apt description. But much more is implied in what I am saying here.

The issue of the dynamics of grieving is simply more complicated than it might appear. I believe that the differences in culture--thus differences in values--influence the process to the point at which any simplistic attitude towards intervention would be inappropriate and possibly harmful. This could be an even more serious problem if intervention were to be based on the commonly held belief that the bereavement process

should be over and done with at the end of the first year or that everyone should have follow-up. The implications for programs of bereavement intervention are considerable indeed.

Before attempting to relate some of the above data to the issue of social policy, a caveat is in order. I trust that no one has the impression that this research was as simple and straightforward as this necessarily factural presentation might imply. It was--and remains--an awesome undertaking, marked by very limited funding, difficult methodological problems, a massive data base, and obstacles of every possible size and shape--not the least being winter weather in Montreal. If any offer of a post in the Arctic region had been made during the more difficult moments, I am certain it would have received due consideration.

I have divided the second section into two parts: the first deals briefly with the research itself as reflecting Canadian social policy, and in a minimal way, influencing that of the United States, and secondly, some specific implications of these data for community intervention.

There is no universal agreement on the definition of policy. As Murrell (1984, p. 186), points out, it generally includes goals, strategies, and values. His statement that the term could perhaps be understood simply as referring to a plan that is consistent with an ideology is most apt for this research, because it is, in effect, an outcome of a policy statement by the Canadian Government.

The British North America Act essentially hinders the central government from imposing values on health care across Canada because health

is a provincial affair. Each province identifies its priorities, values, and types of service delivery systems. Ottawa has great difficulty in imposing any kind of centralized control, nor can it oblige adherence to a single model of delivery service. I might add as an aside, this has had important implications for the development of community psychology in Canada. The Federal Government in Ottawa has thus been limited to public health problems and preventive programs.

The only exception to this limitation has been the development in Canada of universal medicare. As a consequence, the government is interested in preventive programs which would keep people out of hospitals and institutions. The Canadian Federal health policy statement that has strongly influenced this development and resulted in funding for such preventive programs as ours, was the government white paper, in 1974, by the then-Minister of Health, Marc Lalond. The policy statement outlined a rationale for Ottawa to return to its original health mandate to some degree, that is, the development of preventive programs. Individuals should be helped to help themselves, and the role of self-help groups, the use of paraprofessionals and community programs that do not involve professionals were recommended. All of these methods can be recognized easily as basic procedures of community psychology.

As Davidson pointed out in his article on the development of community psychology in Canada (1981) the white paper partly generated and partly reflected a growing belief that we should consider the possibility of changing the social system to fit the individual's needs rather than

using expensive people and resources to treat deviant individuals so that they fit the existing social system. The Lalond paper clearly reinforced the belief that changing environmental hazards and individuals lifestyles may be fiscally and socially more desirable than trying to treat the resulting effects. Thus, in Canada for the past ten years there has been a government policy consistent with social action in the area of prevention. Although, to my knowledge, it has rarely or never been invoked as a basis for social change in the larger context of society, and certainly not during a period of economic recession such as we are experiencing now, it does remain a policy statement of the Federal Government.

When the grant for the bereavement research was accepted, it was undoubtedly due to this government policy, however indirect that link might be in actual fact. In turn, there is the responsibility on our part to complete the project and eventually to implement the findings as much as possible.

At a more concrete level, the research has brought about changes in bereavement follow-up at the Palliative Care Service. The results had indicated that there was no current justifiable basis upon which professionals could be hired for intervention. This work is now done by trained volunteers who, I must emphasize, work with normal, high risk cases, as assessed by the modified Bereavement Coping Assessment, which they themselves undertook to change.

I do believe that the research represents as Iscoe (1984) stated: an attempt to understand and apply psychological knowledge to a given problem--in this case that of bereavement. It also reflects, in a minimal way,

Goldston's coutention that public policy involves the reduction of health care costs (1984).

As for implications of this research for the United States, an event occured which was not due to any effort on our part-- we were and are still too involved with the analyses of the data even to think of its application. We were included in the site visit to the Palliative Care Service, last September, by two members of the Institute of Medicine, of the National Academy of Science. They are preparing a brief on bereavement for the Office of Prevention, of the National Institute of Mental Health. We shared the results available at that time, and although little of the date may find its way into the final report, it was a tremendous source of satisfaction to know that the questions we were studying were directly related to specific issues they had under discussion. There was the sense of having had a word or two in the eventual development of social policy. That day I considered myself to be what Masters (1984) calls, the «lucky researcher», onewhose data appear to have face relevance.

The second incident occurred one week later. It was a very different experience. I had been asked to present the research at a conference on bereavement in palliative care, the first national meeting of its kind in the United States. I was the last, and unknown speaker, in what had been a fullday of presentations by well-know experts on bereavement. The talk included the findings mentioned above but with graphs, statistics, etc. I completed my presentation within the 30 minute time limit and returned to my place at the speakers' table. In that audience of 800 or more, there was complete, total, deafening silence. The chairperson stood, asked for

questions, waited, and the with a certain sense of relief called for a coffee break.

The question period which followed need not be described, but I can say I now know what is meant by a hostile audience. In spite of the specific caveats concerning the limitations of the research, careful explanations of exactly where we were in the analyses, the affirmation that the results did not--could not--in any way be construed as a judgment on the unsefulness of bereavement intervention, but rather with its application, nothing worked. As the volley continued, I began to hypothesize that research might possibly be dangerous for one's health.

The impact of the talk was due to the fact that palliative care units had been implemented in hundreds of hospitals all over the United States. When funded by your Federal Government, it was with the provision that money would not be forthcoming for the bereavement program for at least two years, in order to give that arm of palliative care time to prove its economic necessity and viability as a preventive service. Thus, the results were the exact opposite of what was expected. The problem was compounded by the fact that Dr. Mount's internationally known, pioneering role in palliative care had led them to assume that the results of the evaluation of his program would certainly prove that professional staff should be hired, and for some representatives at that conference, that all families should receive intervention--this was a disturbing talk indeed.

This situation does illustrate the difficulty of going against a strongly held ideology, one with firm conviction that the policy is correct.

These are very dedicated, intelligent, hard-working professionals, but the issues I raised were very threatening and so unexpected. I can well understand why any cognitive appraisal of the situation was out of the question at that moment.

A few individuals later told me that they knew that some of the points reflected their own doubts about the universality of intervention. They admitted that they simply did not want to hear them expressed openly. It was very difficult to be the harbinger of what was perceived as very bad news. But the experience did provide many reasons why I, as a researcher, must periodically reflect on the roles and values involved in studies of this kind.

I wish to conclude with a few reflections which spring from but go beyond the limits of the research data. And I have formulated them from the perspective of my role as a community psychologist.

The key persons in this research had lost a loved one by a death which, in a certain sense, was expected. There was awareness by them, even if denied to the very end, that it was inevitable. If the effects we have seen are the result of what was anticipated, how much more traumatic are the emotional reactions following sudden, unexpected loss, as Benerly Raphael's (1983) excellent volume makes potently clear. The literature on these outcomes is plentiful and the message is: the risk factor for poor outcome is serious. And then there are the deaths by suicide, which leave a legacy of uncertainty, of guilt, of blame, of hostility. The circumstances of the death add to the psychic trauma and the social ostracism which often follows

is a far cry from what we label, "supportive social networks". But the main point is this: I am certain that the majority of the survivors from these deaths are those we call "normal". Yet all the interventions made in these situations are, I would suggest, from the model of treatment, of pathology. I wonder if this is the only way.

It is common knowledge that death affects the family system. It is irrevocably changed. There is some information on different age reactions to loss, although none on the longterm bereavement process of adolescents. If we accept as a given, that the family is a central system within the larger social order, and that loss and separation are inherent in everyone's life, than it would seem imperative that those of us interested in social support and the building of networks accept the responsibility of finding out how the family, as a social unit, responds to the crisis of bereavement. The descriptive study by Pincus (1974) would provide the indications of how this might be accomplished. Other than that, little is known.

The field of bereavement has indeed been a fertile ground for the development of preventive programs which have been efficacious for so many. And professional involvement has been impressive. The groups that work the best reflect what the research on primary prevention makes very clear: Specific programs for specific problems have the greatest effect, if an effect is to found. But belonging to a group indicates sufficient motivation to become a joiner. Yet, the majority of those who are bereaved would appear to be non-joiners. When I consider the 680 individuals who did not choose to participate in this study, I wonder how they have dealt with their losses. Many,

from what we have been able to determine, were either isolated, or felt it was up to them to cope by themselves, or were so angry over the circumstances of the death they wanted nothing to do with us, whom they considered part of the health care system. As for those we were unable to reach, we know only that many had moved away. The effect of these changes on the small neighborhood community is not known.

What I have learned from this research and indicated in the above reflections is how little we know about the effects of death on the individual, on the family, on the community, on society--all of which are essential factors to be considered for the development of social policy for bereavement interventions. We can say that mourning a loss is part and parcel of human existence--that, in general--most people seem to cope, to survive, to integrate the loss and get on with living--and do it quite well. That is undoubtedly true. But it stops short of confronting the real issue: At what price?

The troubling data from some of those 680 non-subjects seem to indicate that it may be a very high price indeed.

In his recent article on the role of psychologists in policy issues, Sarason (1984) states that he expects community psychologists to see any problem in relation to the nature of our society and its communities. He wrote: "Any problem is an instance of a broader set of problems which in turn reflect dynamics of our society (p. 205)."

I believe this is eminently true for the problem of bereavement.

We must see it in relation to the nature of our society--that is, for the most part a death-denying society--with all that that implies; and we must see it in relation to our communities--and what makes up our communities are the family systems, educational institutions, health care facilities, among many others in all of these, the bereavement process for the individual remains a private, lonely, painful affair. Even when concern is expressed and people reach out to the bereaved there is the unspoken hope that the mourning will be over soon-very soon and we can get back to the business of living.

If we accept to understand the problem of the effects of bereavement on society within this perspective of the nature of society and the community and the individual within that society, we must then see how we can go about implementing social policy, that is, applying psychological knowledge towards programs designed to better the human condition.

But where do we begin?

I would suggest that the fundamental and experiential knowledge needed for alleviating the distress of the bereavement process begins within each of us--as unique individual human beings. Whether we admit it or not, the losses due to separations of many kinds, and those from significant deaths have influenced who we are and how we act. Reflection on how we coped--what helped--and what hindered that coping, is, I would suggest, a necessary first step. This is not a social problem which happens to others--it happens to us too. Without this basic knowledge--which implies the acceptance of loss as a reality in our lives--I find it difficult to see how we can reach out to

others in need. Perhaps it is only after that first step and when we have integrated that human experience into our professional identity will we be of service to the communities wherein we not only work, but where we live as well. The awareness of both love and loss in our lives should help us be sensitive to what bereavement is all about.

Only then, perhaps, can we strive to implement services in our roles as community psychologists. Anderson sums up very succently the essence of what I am saying:

"Death ends a life, but it does not end a relationship, which struggles on in the survivor's mind, toward some resolution, which it never finds (1974, p. 77)."

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